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HEAL Project

Community Outreach Program in Education (COPE) Series

A Case in Point:

This example, adapted from a case analyzed in The New England Journal of Medicine *(Morrison et al. 1996) illustrates aggressive medical culture, non-beneficial and even inhumane technical interventions, and disregard for patient and family concerns and preferences.*

Solomon Katz, a 75-year-old retiree, was diagnosed with lung cancer that had metastasized to the brain. After his diagnosis hospital staff described him as "in denial," but a psychiatric consultant assessed him as reacting appropriately and capable of making his own decisions. He revealed that his wife had died of cancer two years earlier and he did not wish to go through similar suffering.

The staff offered him options for life-prolonging but invasive treatment; he declined. The medical staff did not refer him to the hospital's social work staff, and no one sat down with him and his family to talk with them about the prognosis, palliative care options, or their concerns and preferences.

He was discharged and returned three months later following grand mal seizures. The neurology team wanted to operate on his brain tumor but his son refused and asked for a do-not-resuscitate order on the basis of his father's previously expressed wishes.

During the next three weeks he was minimally responsive but repeatedly removed a nasal feeding tube despite restraints. After pressure from the hospital staff, the son agreed to the insertion of a feeding tube that was put through his skin so it could not be easily removed. The next day his father died of cardiac arrest with no family present.

The son was very upset by the entire experience. His father's dying could have been a less brutal experience. His care could have been managed differently with an emphasis on understanding his father's goals as his life ended and providing physical and emotional comfort.

adapted from
Approaching Death --
Improving End of Life Care

Caring for a Terminally-Ill Loved One:
You and the Health Care System

Due to technical advances in medicine, death has moved out of homes and into institutions. In the last half century the percentage of deaths in institutions has nearly doubled to about 75%. This is significant because decisions by health plan managers and institutional administrators often impede the ability of patients to receive care that serves the dying person well. It is the purpose of this issue to highlight some of the potential barriers to receiving compassionate end of life care for your loved one.

In the U.S. the marvels of medical technology have convinced many health care professionals that "letting nature takes its own course" is simply not an option. This philosophy often leads to an impersonal and unwittingly cruel death where patients often appear as augmentations of the very equipment that is keeping them alive – tubes and wires everywhere. One 1993 study in the *American Journal of Public Health* reported that nearly half of the physicians and nurses interviewed admitted to having acted contrary to their consciences, mostly providing overly burdensome treatment.

End of life care most commonly takes place in either hospitals, nursing homes or through hospice care inside or outside of the home. Let's take a closer look at the each one of these options.

Hospitals – more deaths occur here than in any other setting. As a caregiver who is making decisions for your loved one, it is important to understand that the principal missions of a hospital are to cure disease and prolong life. Therefore hospital culture often views death as a failure instead of a naturally occurring event that occurs in everyone's life. Modern medicine has been very successful in rescuing, stabilizing, or curing people with serious medical problems. So it is understandable that the hospital is often the first place we think of when looking for a setting that can provide our loved one with end of life care. The *Case in Point* in the column to the left illustrates what can happen in a hospital.

Nursing Homes – nursing homes differ from hospitals in many respects, including low level of physician involvement, much lower ratios of registered nurses per resident, and the amount of care that is provided by nursing assistants. Nursing homes are often criticized for not being home-like and having low quality nursing care. Studies have found that nursing home residents often suffer from inadequate pain management.

Hospice – hospices are organizations concerned exclusively with the care of the dying. To be admitted to a hospice your loved one must have received a prognosis of 6 months or less from their physician. Hospice care is usually intended to help people die comfortably at home or in a residential hospice (inpatient facility). Studies have found that too many people suffer needlessly at the end of life due to pain associated with their illness. This is where hospice excels in comparison to the previous two options. Palliative care (pain management or comfort care) is a principal focus at hospice with a goal of providing the highest quality of life for the remaining time the dying person has with their loved ones.

Later issues of this **COPE** series will address various aspects of end of life care in more detail. The following are key elements to look for in choosing end of life care options:

- Symptom prevention & relief
- Attention to emotional & spiritual needs
- Care for patient & family as a unit
- Sensitive communications
- Interdisciplinary care
- Flexible care for special needs of the dying

I cannot pretend to speak of death as a misfortune…Death is the arch of triumph under which the soul passes to live again in a purer and freer atmosphere.

Florence Nightingale